



## Welcome!

We appreciate your participation in this scientific conference, *Health Disparities in Arthritis and Musculoskeletal and Skin Diseases*. Those interested in the Nation's health have become increasingly aware of disparities among different population groups. The Department of Health and Human Services' public health initiative, *Healthy People 2010*, provides a plan for the Nation's public health goals for the next 10 years that addresses many challenges in populations defined by ethnicity, gender, and age. The overarching themes of this national effort are to eliminate health disparities and to increase quality and years of healthy life. For the first time, arthritis and musculoskeletal conditions are identified in a major public initiative as distinct and important concerns warranting monitoring and intervention measures.

The goals of this conference are to review current knowledge about health disparities in arthritis and musculoskeletal and skin diseases and promote new research opportunities and approaches to eliminating disparities in the frequency and course of these diseases in ethnic groups at increased risk. Objectives of the conference are to

- Highlight current knowledge about genetic, environmental, social, and behavioral factors that play a role in the marked differences in the prevalence, morbidity, and disability associated with arthritis and musculoskeletal and skin diseases
- Identify intervention strategies that could provide models to reduce disparities, and identify barriers to dissemination of these strategies
- Define challenges and emerging opportunities for research in these areas.

We will publish reports of this conference in professional journals, including *Arthritis and Rheumatism*, and make a summary available on our Web site (<http://www.nih.gov/niams>). This conference will also be available for viewing on the Internet during and after the meeting at <http://videocast.nih.gov>.

This conference is dedicated to determining what we know and what we need to know to reduce disparities in arthritis and musculoskeletal and skin diseases and to disseminating what we learn. We are enthusiastic about and committed to this process and thank you for joining us.

Sincerely,

Stephen I. Katz, M.D., Ph.D. Matthew H. Liang, M.D., M.P.H. Reva C. Lawrence, M.P.H.  
Director Conference Chair Conference Program

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# Health Disparities in Arthritis and Musculoskeletal and Skin Diseases

December 15-16, 2000

National Institute of Arthritis and Musculoskeletal and Skin Diseases  
National Institutes of Health  
Natcher Conference Center

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Friday, December 15

## AGENDA

7:30 Registration

**Welcome and Introductions**

8:00 Stephen I. Katz, M.D., Ph.D.

**Welcome**

8:05 Ruth L. Kirschstein, M.D.

**Opening Remarks**

8:10 David Satcher, M.D., Ph.D., Assistant Secretary for Health and Surgeon General, U.S. Department of Health and Human Services

**Background and Introduction**

8:25 Matthew H. Liang, M.D., M.P.H., Conference Chair

**I. Measuring and interpreting observed disparities in prevalence and severity of disease, access to health services, and health outcome**

8:30 **Session Chair:** Raynard S. Kington, M.D., Ph.D.

**Presentations**

1. Defining race and ethnicity—Graciela S. Alarcón, M.D., M.P.H.
2. Assessing skin conditions in people with different skin hues: The NHANES Validation Study—Alexa Boer Kimball, M.D.; Natalie Dupree, M.S.
3. Differences in skin and hair structure between ethnic groups: Disparities in knowledge and research—Susan C. Taylor, M.D.
4. Disparities in orthopaedic procedures by age, sex, and race—James N. Weinstein, D.O., M.S.
5. Ethnic differences in radiographic hip and knee osteoarthritis (OA): The Johnston County Osteoarthritis Project—Joanne M. Jordan, M.D., M.P.H.

10:00 **Panel:** Speakers; Molly T. Vogt, Ph.D.; Tim Carey, M.D., M.P.H.; C. Kent Kwoh, M.D.

10:30 **BREAK**

**II. Genetic and environmental factors leading to disparities**

10:45 **Session Chairs:** Patricia A. Fraser, M.D., M.P.H., M.S.; Elizabeth W. Karlson, M.D.

**Presentations**

10:55 1. Wound healing and keloids—A. Paul Kelly, M.D.  
11:05 2. Ethnic differences in genetic, sociodemographic, immunologic, and behavioral factors in systemic sclerosis—John D. Reveille, M.D.  
11:15 3. Genetic variations of receptors for immunoglobulin (FcγR): Determinants of severity of systemic lupus erythematosus (SLE)—Jane E. Salmon, M.D.  
11:25 4. Environmental risk factors for human and murine lupus—Evelyn V. Hess, M.D., M.A.C.P., M.A.C.R.  
11:35 5. Risk factors for SLE in the Carolina Lupus Study: Does anything explain the racial disparity in disease?—Glinda S. Cooper, Ph.D.  
11:45 6. Genetic and environmental risk factors for lupus and other connective tissue diseases (CTDs)—Patricia A. Fraser, M.D., M.P.H., M.S.  
11:55 7. Ethnic differences in cartilage oligomeric matrix protein (COMP) and its association with osteoarthritis: The Johnston County Osteoarthritis Project—Joanne M. Jordan, M.D., M.P.H.

12:05 **Panel:** Speakers; E. Nigel Harris, M.D.

12:30 *LUNCH*

**III. Social and behavioral factors influencing the frequency and impact of disease**

1:30 **Session Chair:** Kate Lorig, R.N., Dr.P.H.

**Presentations**

1:45 1. Physician/patient satisfaction with cross-cultural clinical encounters—JudyAnn Bigby, M.D.  
2:05 2. Ethnic differences in management of OA—C. Kent Kwoh, M.D.  
2:25 3. Race and its relationship to prevalence, care-seeking, and care patterns in low back pain—Tim Carey, M.D., M.P.H.  
2:45 4. Racial differences in pain, physical disability, psychological disability, and coping in OA—Christopher L. Edwards, Ph.D.

3:05 *BREAK*

3:20 5. Ethnicity, self-management, and self-efficacy—Kate Lorig, R.N., Dr.P.H.  
3:40 6. Complementary and alternative medicine use in different ethnic groups—Leigh Callahan, Ph.D.  
4:00 7. Addressing barriers to care in a culturally diverse indigent population: The Los Angeles County Rheumatoid Arthritis Health Project—Andrew L. Wong, M.D., F.A.C.P., F.A.C.R.

4:20 **Panel:** Speakers; Graciela C. Alarcón, M.D., M.P.H.; Elizabeth W. Karlson, M.D.; Said Ibrahim, M.D., M.P.H.; Dorothy Dunlop, Ph.D.; Judith Horstman, M.A.; Agustín Escalante, M.D.

5:30 *Adjournment (reception immediately follows)*

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**Saturday, December 16**

**AGENDA**

**IV. Strategies to eliminate disparities**

8:00      **Session Chairs:** Joanne M. Jordan, M.D., M.P.H.; Matthew H. Liang, M.D., M.P.H.

**Presentations**

- 8:15      1. Understanding disparities in ethnic populations—Ana F. Abraido-Lanza, Ph.D.
- 8:35      2. Literacy programs—Lawren H. Daltroy, Dr.P.H.
- 8:55      3. A community model for Spanish language arthritis program delivery and evaluation—Lori Harrison Port, B.S., M.P.H.
- 9:15      4. Outreach models for culturally diverse populations: Laying the groundwork for evaluating programs to correct disparities—Laura Robbins, D.S.W.
- 9:35      5. Outreach models for African American communities—Oretta Mae Todd, Ph.D., M.S.N., C.N.M.; Gillian R. Barclay, D.D.S., Dr.P.H.

10:10      ***BREAK***

10:25      **Panel:** Speakers; JudyAnn Bigby, M.D.; Augustus A. White III, M.D., Ph.D.

**V. Research opportunities to eliminate disparities**

10:55      **Session Chairs:** Joanne M. Jordan, M.D., M.P.H.; Matthew H. Liang, M.D., M.P.H.

11:30      Adjournment

## Defining Race and Ethnicity

Graciela S. Alarcón, M.D., M.P.H.

The terms race and ethnicity are oftentimes used interchangeably; in fact, they should not be, since they are two different constructs. Race is a biologic concept used to describe a uniform, closely inbred group of people (which is rarely the case in humans). Lacking such attributes, individuals are classifying as belonging to a given race based on their physical, psychological and even moral attributes. Race is therefore neither a natural nor a neutral construct. Ethnicity is, in contrast, a social construct, which indicates the presence of common values, national or geographic origin, language, etc among a group of individuals. These common features are the source of identity for the group, as well as for its members. Although four major racial groups were recognized in the 1700's when the term was first used (Caucasian, Asian, African and American-Indian), the 1990 US Census recognized about 300 different racial groups. However when these different groups are examined closely, it is clear that the correct term which should be used to define them, is that of ethnicity and not of race.

In the clinical setting, race (without defining it) is used on a daily basis; although in certain circumstances it may aid in establishing a diagnosis (diseases occurring more frequently in certain racial groups), in the vast majority of cases, it does not add much to the patient's diagnosis or management. Moreover, confusion arises when individuals are erroneously classified based on their physical appearance and a diagnosis either ruled in or out because of such racial attribution. This confusion is not limited to direct patient care; it also occurs with vital statistics, which are by no means flawless. It has been shown, for example, that race-specific infant mortality rates tend to underestimate these rates for non-Caucasian infants (infants classified as non-Caucasian at birth, but Caucasian at death).

In the research setting, race and ethnicity are used interchangeable and in the vast majority of cases neither term is defined. Efforts to study genetically homogenous groups of people based on the "racial" background of the four grandparents are laudable, but by no means guarantee than such homogeneity will be achieved. Nevertheless, conclusions are reached among given "racial/ethnic" groups based on such characterization, sometimes without consideration given to the socioeconomic and cultural characteristics of the individuals constituting the group. Given the strong association between some "racial" groups and socioeconomic status (SES), the contribution of race and SES to disease outcome is difficult to sort out. It has been proposed by some investigators to eliminate the use of race and ethnicity altogether, instead to more precisely define the socioeconomic and demographic features of the individuals being studied. The strong association between SES and ethnicity, however, justifies the use of this variable in both the clinical and research settings, if disparities in the access and delivery of health care among majority and minority ethnic groups are to be eliminated, and the overall health of the population is to improve.

## Assessing Skin Conditions in People with Different Skin Hues: The NHANES Validation Study

Alexa Boer Kimball, M.D.; Natalie Dupree, M.S.

National health examination surveys have been conducted periodically in the United States since 1960. The National Health and Nutrition Examination Survey (NHANES) assesses the health and nutritional status of adults and children in the United States through questionnaires and health examinations. In 1999, NHANES took a new direction by becoming a continuous survey. The sample design is structured so that each year of data will be a nationally representative sample of the U.S. population. The eligible population for this survey consists of the civilian, non-institutionalized population in all states and the District of Columbia. The current survey was designed to over-sample African Americans and Mexican Americans. The examination portion of the survey is conducted in specially designed trailers called Mobile Examination Centers (MECs). The goals of the current survey include - to study relationships between diet and health; to explore emerging public health issues; to establish a national probability sample of genetic material for future research; to establish and maintain a national probability sample of baseline information on health and nutritional status; to estimate the number and percent of persons in the population and designated subgroups with selected diseases and risk factors; to monitor trends in the prevalence, awareness, treatment, and control of selected diseases; to monitor trends in risk behaviors and environmental exposure; and to analyze risk factors for selected diseases. One new topic that has been proposed for inclusion in NHANES is a dermatological assessment.

One of the challenges in evaluating health disparities in dermatological assessment has been the difficulty in accessing an adequate number of people with different skin hues, but with the same dermatological condition, in a clinical setting. Because NHANES over samples African Americans and Mexican Americans, this survey provides a unique opportunity to examine large numbers of people with a range of skin hues in the same setting. However, there are some issues and constraints in the NHANES, including exam time constraints; technological issues; limited access to medical history; lack of follow-up; confidentiality issues; and reproducibility that can have various effects on the data collection and interpretation.

A study was designed to evaluate the sensitivity, specificity, validity and reliability of digital photography of the skin as an assessment tool to evaluate the prevalence of dermatological conditions in the NHANES. The three skin disorders studied were atypical nevi, psoriasis, and hand dermatitis. These conditions were selected based on their expected importance in the U. S. population, including a prevalence of 3-10%, associated risk of melanoma in the case of atypical nevi, and associated disability in the cases of psoriasis and hand dermatitis.

In the first phase of this study, over 500 subjects were examined, photographed, and had their skin coloring assessed by spectrophotometer during the course of a 3-day skin cancer screening. Four photographs were taken of six body regions, based on the anatomic distribution of the three conditions under study, the need to maximize the information obtained in the context of NHANES logistical limitations, and the requirement to maintain patient privacy. The results indicated that use of this technique would be feasible in the NHANES health examination

component. The study was designed to have four standardized images evaluated by independent clinical dermatologists. The photographic findings will be compared to those of corresponding physical exams and the spectrophotometric data to determine the validity of this approach.

## Differences in Skin and Hair Structure Between Ethnic Groups: Disparities in Knowledge and Research

Susan C. Taylor, M.D.

The population statistics of the United States reveal dramatically shifting demographics in the twenty-first century which will significantly impact upon the practice of dermatology. A review of the United States Census population data of July, 1990 revealed that non-Hispanic Whites comprised 75.6% of the population with 11.8% of the population classified as Black, 9% of Hispanic origin, 2.8% classified as Asian and Pacific Islander and 0.7% American Indian, Eskimo and Aleut. In sharp contrast, the United States population projections for the year 2050, forecasts a significant decrease of the non-Hispanic white population to approximately 52.8% of the total population and concomitant increases in the other segments of the population as follows: the Black population increases to 13.6%, Hispanics to 24.5%, Asians to 8.2% and American Indian, Eskimo and Aleut to 0.9%. In slightly under a century, the non-white population will increase from one quarter of the overall US population to approximately one half of the population.

These changing demographics highlight the need for and importance of a thorough understanding of non-white skin which we will term skin of color. On a basic science level, a complete understanding of the structure, function and biology of skin and hair of people of color is fundamental before we are able to fully understand the cutaneous diseases that affect pigmented skin or the treatment of those diseases.

When attempting to understand skin of color, the first question that one must ask is if there is scientifically based data demonstrating differences in the structure, function and biology of skin and hair of people of color as compared to white individuals. If the data exists, then is the underlying science unbiased and sound. There is overall a marked paucity of skin of color basic science research as evidenced by the limited literature citations available. Many of the basic science research studies involving the structure of skin of color date back to the early part of this century, involve small numbers of subjects and are fraught with bias because of the commonly held belief at that time that individuals with skin of color were genetically inferior. This is indeed the case when we attempt to understand the human cutaneous appendages, the apocrine, eccrine and sebaceous glands. There is a longstanding perception in the dermatologic and scientific communities that people with black skin have increased numbers of eccrine and apocrine sweat glands and a concomitant increase in the activity of those glands. This would place individuals with skin of color closer to non-human mammals who have abundant apocrine glands over their entire body surface. Scientific determinations that people of color have larger and more apocrine glands than whites would support the belief that people of color are inferior to white people.

The human apocrine gland, located primarily in the axillae and perineum and to a lesser extent in the umbilical and areolar areas, most likely has an odoriferous function. A review of the literature pertaining to apocrine gland structure and function between the races reveals only three studies. The first of the three studies in the literature investigating this gland was published in 1922 by Dr. Schiefferdecker. His histologic evaluation of the apocrine gland of three Negroes,

one Chinese and twelve white Germans concluded that the Negro race had increased numbers and larger apocrine glands than either the one Chinese or the twelve white subjects studied. Of note is the fact that this frequently quoted conclusion concerning racial differences in apocrine gland number and size was based upon evaluation of only sixteen patients.

Dr. Homma in 1926 viewed histologically 538 sections from whites subjects and 631 sections from Negro subjects from four apocrine bearing areas of the body and found that apocrine glands occurred three times as often in the Negro as compared to the white subjects. However, none of the specimens were obtained from the axillae of these individuals which is the area of the body which contains the greatest number of apocrine glands and indeed should be the exclusive site of a racial comparative analysis.

The final study performed in 1960 by Hurley reported profound racial differences in apocrine gland size and function with blacks reportedly having larger apocrine glands than whites. This same group also looked at apocrine sweat production in a sample size of thirty white and Negro subjects with the Negro subjects reportedly producing greater quantities of apocrine sweat which was described as more turbid and produced a "unique axillary odor" as compared to the white subjects. These limited data highlight the need for blinded, scientific investigations involving larger numbers of subjects from each of the various racial groups.

I will next use the commonly occurring disease in skin of color, acne vulgaris to highlight disparities in knowledge and research on both a basic science and clinical level. The relationship between a firm knowledge of the structure and function of skin of color and understanding cutaneous disease is evident when we look at the sebaceous gland and its relationship to the disease acne vulgaris. The studies of racial differences in sebaceous gland activity are sparse and contradictory. Differences in sebaceous gland size and activity between black and white skin have been suggested. Nicolaides (1952) concluded that black subjects had increased sebum production as compared to white subjects by measuring increased fat level in the hair of the Negro subjects (60 to 70 % more hair fat as compared to the whites). Differences in hair weight, size and diameter between the races were not factored into the determinations. Furthermore, the hair oil levels are probably not an accurate measure of either sebum production or sebum levels as they may, in fact, only reflect the follicular reservoir of sebum. Kligman (1958) determined sebaceous gland size and activity by first measuring surface sebum levels during a four-hour period in five black and five white subjects. The results of those ten patients indicated that the black subjects had higher surface sebum levels than the white subjects did. Furthermore, by obtaining forehead biopsy specimens from two black subjects that produced high or moderate levels of sebum and two white subjects that produced low sebum levels, Kligman determined that the black subjects had huge sebaceous glands in comparison to the white subjects. Champion (1970) determined that the sebaceous glands of blacks were larger but no more numerous than in whites.

Pochi (1988) measuring sebum production on the foreheads of a small number of blacks subjects showed that in their 30 Black male subjects, the mean sebum production was slightly but not statistically increased as compared to the 373 white male subjects. In one group of their female subjects ages 18-29, the opposite results were obtained revealing that sebum levels were lower at a statistically significant level in the 25 Black women as compared to the 157 white women. The

sebum production values for each of the 67 black subject in Pochi's study were assessed to determine whether they lay within the 95% limits using the 582 white subjects as the control group. Only four of the 67 black subjects had sebum production values that exceeded the range of two standard deviations from the mean of the white patients. Abedeen (1999) in a poster exhibit at the American Academy of Dermatology determined the rate of sebum excretion in 20 white, 20 black and 20 Asian subjects by measuring sebum utilizing both sebutape and a sebumeter. He concluded that there was no statistical difference in sebum excretion rate between ethnic groups.

These studies comparing sebaceous gland size and activity between white and black subjects involve such small numbers of subjects that accurate conclusions cannot be drawn. Furthermore, other than the American Academy of Dermatology poster, we have been unable to obtain comparative studies investigating sebaceous gland size and sebum levels in Latino or Asian patients. Therefore, it remains uncertain if individuals with darkly pigmented skin produce more or less sebum than those with white skin. Obviously, further investigations are needed to resolve this question. Furthermore, since the production of sebum is a determining factor in the development of acne vulgaris, predictions concerning racial and ethnic trends in the development of acne cannot be made.

When one examines the prevalence data involving acne vulgaris there are several published studies to draw upon. A search of the literature reveals several surveys of the prevalence of acne vulgaris in black, white, Asian and Arab private or clinic practice populations both in the United States and abroad. It is important to note that surveys of the epidemiology of acne vulgaris in private and clinic populations will only suggest trends. The frequency of acne vulgaris in various racial and ethnic groups can only be determined by large population surveys. To my knowledge, there are no population surveys published determining the prevalence of acne in the general population.

The first of these survey studies by Fox (1908) determined that in 2000 white and 2200 black patients, acne occurred in 163(7.4%) of the white patients and in 101(4.6%) of the black patients. Hazen (1914) comparing 2000 black and 2000 white dermatology outpatient visits, concluded that acne is almost as common among blacks as among whites, with acne constituting 8.4% of all black cases seen (169 black and 180 white acne patients). Kenney (1965) tabulated from his private practice the diagnoses of 3860 consecutive black patients and compared those diagnoses with 27,000 diagnoses compiled by Welton (1960) and determined that 9.0% of his black patients and 18.0% of the white patients had a diagnosis of acne. Acne was the third most common diagnosis in the black patients and the first most common diagnosis in the white patients. Several more contemporary studies are as follows. Halder (1983) studied 2000 black private patient diagnoses and compared them with the diagnoses of 550 white private patient diagnoses. Halder determined that 27.7% of the black patients and 29.5% of the white patients had a diagnosis of acne which was the most common diagnosis in both groups. Childs (1999) in the United Kingdom recorded the diagnosis of 274 adult black patients and determined that 13.7% of those patients had acne vulgaris (the most common diagnosis). Childs also compared the annual percentage of referrals for acne vulgaris in different ethnic groups and determined that 51% of the patients seen for acne vulgaris were black, 41% were white and 8% were Asian or Arabic.

Goh (1994) surveyed 74,589 Asian patient visits (Chinese, Malay, Indian) in Singapore and determined that 10.9% of the adult population had acne (the second most common diagnosis) and 3.1% of the pediatric population had a diagnosis of acne (the eighth most common diagnosis). Although no data on adult Arabs was obtainable, a survey of 10,000 Arab pediatric cases by Nanda (1999) in Kwait, revealed that acne vulgaris was the third most diagnosis among preadolescent females (ages 10-12) occurring in 10.5% of the cases. Lawrence (1983) reviewed a total of 2821 white and black pediatric patient visits in the United States and determined that acne was the fourth most common diagnosis with 142 cases and that 49.3% of the cases occurred in the black children and 50.7% occurred in the white children. Thus, acne vulgaris is a common skin disorder in individuals with skin of color for which these patients seek dermatologic care. Office and clinic practice prevalence data suggest that acne may occur less often in darkly pigmented skin than in white skin. However, sufficient data from the general population do not exist to determine if acne is more or less common in darkly pigmented skin compared to white skin. Given the projected United States population shifts, it appears that dermatologists will treat increasing numbers of acne patients with skin of color.

The four well described types of acne lesions have been observed in individuals with darkly pigmented skin. These lesions include the comedo, papule, pustule and the nodulocystic lesion. In darkly pigmented skin it is important to add a fifth lesion, that is, the hyperpigmented macule. To our knowledge, no information on the prevalence of the various types of acne either comedonal, papular or pustular is available for white or darkly pigmented individuals. Wilkins while studying the prevalence of acne vulgaris in a prison population of 4000, observed that black male prisoners were less likely to experience severe nodulocystic acne than the white prisoners. This isolated data concerning one type of acne has not been confirmed or refuted in a scientific fashion nor have females been looked at. Research looking at prevalence and incidence studies of acne and the various types of acne is needed. Attitudes concerning physician selection of therapy for patients with skin of color have yet to be scientifically investigated. Again using acne as a model, isotretinoin was determined by Dr. A. Paul Kelly to be as safe and as effective a treatment in black patients as it is in the white patients with acne vulgaris. Prescriptions statistics derived from the IMS National Diagnosis and Therapeutic Index indicate that Accutane for the treatment of acne vulgaris is infrequently prescribed for individuals with darkly pigmented skin especially those of African American descent. An analysis of the Accutane prescriptions filled in 1999 by ethnic group and contrasted with acne office visit statistics is as follows.

#### Accutane Prescriptions

88.3% Whites
4.4% Asian Americans
4.9% Hispanic Americans
2.4% African Americans.

#### Acne Office Visits

83.6% Whites
4.0% Asian Americans
4.7% Hispanic Americans
7.7% African Americans

Accutane is clearly prescribed less often for African American acne patients. Since it has been established that in darkly pigmented skin, acne is a common dermatosis and isotretinoin is an effective therapy in this skin type, reasons for fewer prescriptions filled may include: a lower

frequency of nodulocystic acne (the primary indication for Accutane therapy) in darker skin, lack of knowledge by physicians that Accutane is an effective form of therapy in patients with darkly pigmented skin or perceptions that African American women will not reliably use two forms of contraception while taking the drug.

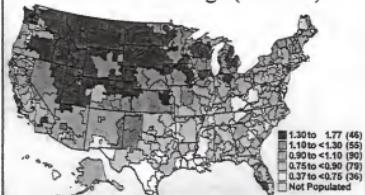
Other areas of incomplete or confusing information concern the structure of the stratum corneum and epidermis as well as the function of those structures as it relates to barrier function and contact dermatitis. Further research is needed. Although basic science information concerning differences in hair follicle and hair shaft structure between the racial groups exists, the etiology of a profound and commonly occurring alopecia in Black women is yet to be elucidated. Finally, diseases such as vitiligo which is felt not to occur more commonly in individuals with skin of color but which is visually more apparent in those individuals more research into etiology, and therapeutic modalities.

## Disparities in Orthopaedic Procedures by Age, Sex, and Race

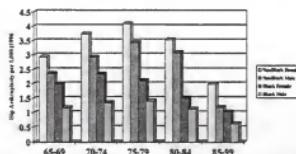
James N. Weinstein, D.O., M.S.

## TOTAL JOINT ARTHROPLASTY

### Ratio of Rates of Hip Arthroplasty to the U.S. Average (1996-97)



### Hip Replacement by Age, Sex and Race (1996)



### Disparity in Females

#### Hip

\*3.26/1000 white females

1.80/1000 non white females

#### Knee

5.89/1000 white female

4.69/1000 non white female

### Disparity in Males

#### Hip

2.75/1000 white males

1.14/1000 non white males

#### Knee

\*4.96/1000 white males

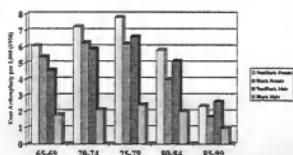
1.86/1000 non white males

There is little evidence to suggest that there are differences in the incidence of degenerative joint disease based on race or geographic location

Ratio of Rates of Knee Arthroplasty to the U.S. Average (1996-97)



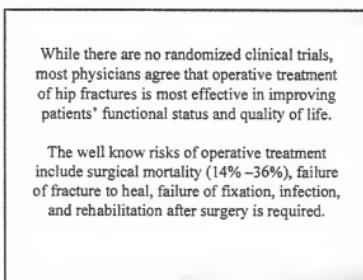
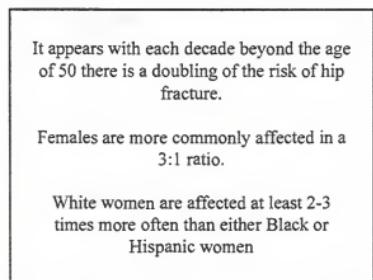
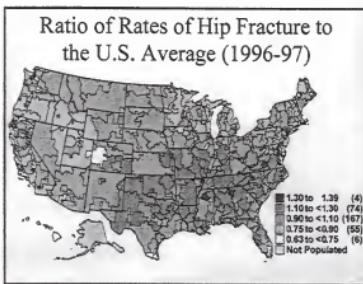
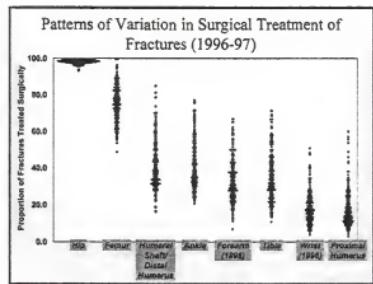
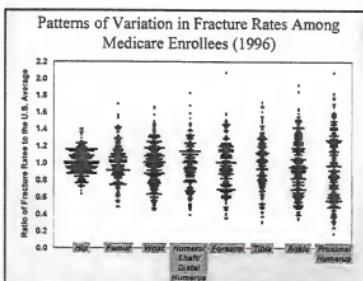
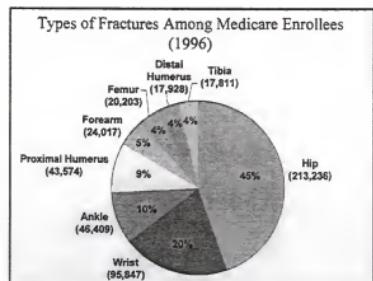
Knee Replacement by Age, Sex and Race (1996)



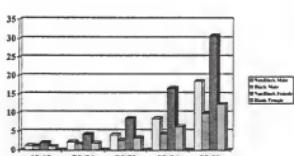
## FRACTURES

Unlike surgical treatments, fractures are not elective. The incidence of fracture increases with age. 65 to 99 year old women have a much greater risk of fracture (4:1), and whites are much more likely to fracture than non-whites (18:1).

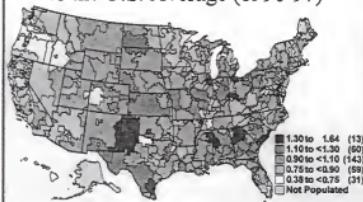
Even accepting increased risk from osteoporosis and age there is often an associated event that leads to fracture. It appears that aging increases the risk of falls, and women may fall more than men.



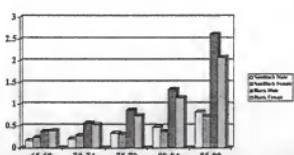
### Femoral Neck/Intertroch



### Ratio of Rates of Femur Fracture to the U.S. Average (1996-97)



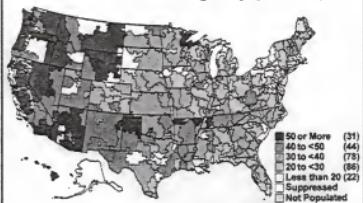
### Femur Below Intertroch



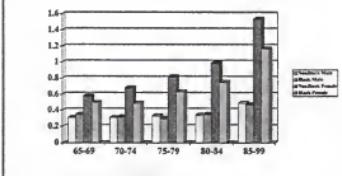
### Ratio of Rates of Tibia Fracture to the U.S. Average (1996-97)



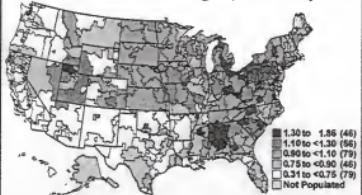
### Proportion of Proximal Tibia/Tibial Shaft Fractures Treated Surgically (1996-97)



### Proximal Tibia & Tibial Shaft



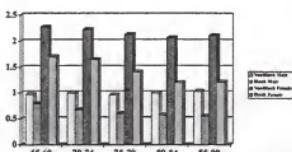
Ratio of Rates of Ankle Fracture to the U.S. Average (1996-97)



Proportion of Ankle Fractures Treated Surgically (1996-97)



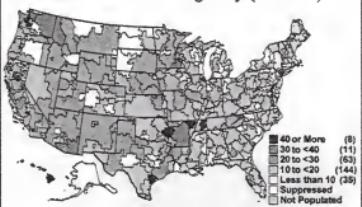
Ankle



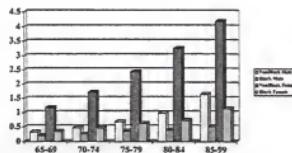
Ratio of Rates of Proximal Humerus Fracture to the U.S. Average (1996-97)



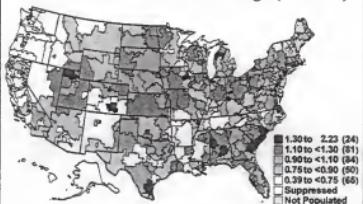
Proportion of Proximal Humerus Fractures Treated Surgically (1996-97)



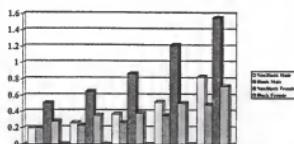
Proximal Humerus



Ratio of Rates of Distal Humerus/Humeral Shaft Fracture to the U.S. Average (1996-97)



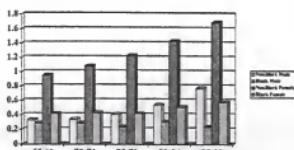
Humeral Shaft/Distal Humerus



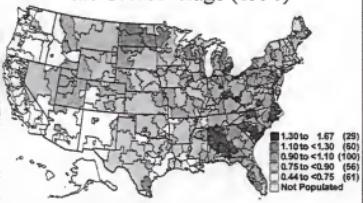
Ratio of Rates of Forearm Fracture to the U.S. Average (1996)



Proximal Forearm/Shaf



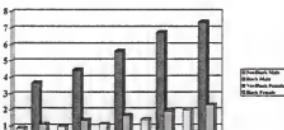
Ratio of Rates of Wrist Fracture to the U.S. Average (1996)



Proportion of Wrist Fractures Treated Surgically (1996)



### Wrist

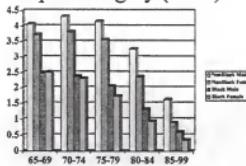


### SPINE SURGERY

#### Ratio of Rates of Spine Surgery to the U.S. Average (1996-97)



#### Spine Surgery (1996)



### Disparity in Spine

We have studied the bone mineral density (BMD) of the lumbar spine in two healthy populations groups in Spain with similar characteristics but with different socioeconomic levels. BMD was measured in 1116 individuals of both sexes in two selected groups: (A) 832 volunteers in the urban Barcelona area and (B) 284 volunteers from a suburb with lower socioeconomic level. Individuals of group A have greater spine BMD than group B. The maximum difference was found in the group between 20 to 39 years: 5% ( $P$  less than 0.001) in mean and 3% ( $P$  less than 0.05) in SD. The decrease in BMD in both groups was similar in rate and quantity, suggesting a possible developmental cause for this difference. Bone loss in women began before the menopause and increased considerably in the following years. The BMD values show that most people at advanced age from the low socioeconomic group cross the fracture threshold earlier than the first group.

del Rio Barquero L, Romera Baures M, Pavia Segura J, et al. Bone mineral density in two different socio-economic population groups. *Bone & Mineral* 1992 Aug;18(2):159-68.

### Disparity in Spine

The relationship between the real results of corrective fusion of the lumbar spine and social and economic factors was investigated. The study consisted of 133 patients operated on in 1986-97. The social background of 116 patients was clarified by the use of questionnaires in connection with the follow-up examination period 4.8 years postoperatively, on an average. The data were classified as far as possible according to the same principles as were used in the Finnish census of 1970. This was possible in 95% of the present series with a high positive value. The average educational level and socioeconomic level were found to be lower in this series. Divergences were more frequent, and the households were larger than in the population at large. Moreover, the age groups 20-39 and 40-49 years were over-represented. The end-results, however, were not correlated to any of these socio-economic factors. In contrast, with educational level, the kind of pre-operative treatment, social group, number of children and size of the place of residence. It is concluded that social factors ought to be considered when selecting patients for lumbar spinal fusion, even if an operation appears to be warranted on medical grounds alone. In addition, the importance of comprehensive rehabilitation for patients with low back pain is emphasized.

Tunturi T, Patiala H. Social factors associated with lumbar spinal fusion. *Scandinavian Journal of Rehabilitation Medicine* 1980;12(1):17-23.

## **Ethnic Differences in Radiographic Hip and Knee Osteoarthritis: The Johnston County Osteoarthritis Project**

Joanne M. Jordan, M.D., M.P.H.

Data on whether different proportions of black and white men and women are affected with radiographic knee and hip osteoarthritis (OA) are conflicting. Studies from Africa and the Caribbean suggest that blacks have a low prevalence of hip OA (1 – 4%), compared to European Caucasians (7 – 25%) (1). Data in the first National Health and Nutrition Examination Survey (NHANES-I, 1971-1975), showed that black women had twice the rate of knee OA as white women (2) and that there were no ethnic differences in hip OA, although the sample was limited by few cases of hip OA and low proportions of African Americans (3). More recently, data from Michigan have shown African American women to have approximately three times the prevalence of knee OA as Caucasians(4). We examined ethnic differences in radiographic knee and hip OA in the Johnston County Osteoarthritis Project (5).

**Methods:** Gender-specific multiple logistic regression was used to assess the role of ethnicity (African American vs. Caucasian) in radiographic knee and hip OA (Kellgren-Lawrence [K-L] grades 2-4), bilateral knee and hip OA, and severe knee and hip OA (K-L grades 3, 4), while controlling for age group (45-54, 55-64, 65-74, 75+ years), body mass index ( $\text{kg}/\text{m}^2$ ), and education (completion of high school vs. non-completion).

**Results:** The sample ( $n = 3,145$ ) was 32.4% African American and 62.2% female. While there were no ethnic differences in hip OA, bilateral hip OA, or severe hip OA in the women, African American men were 35% more likely than Caucasian men to have hip OA (adjusted Odds Ratio [aOR] = 1.35, 95% CI = [1.00, 1.81]).

African American women were more likely than Caucasian women to have knee OA ( $p = 0.05$ ), bilateral knee OA and more severe knee OA ( $p < 0.005$ ), but there were no ethnic differences in women for these knee OA outcomes after adjustment. In men, similar proportions of African Americans and Caucasians had knee OA, but African American men were more likely to have bilateral knee OA (aOR = 1.65, 95% CI = [1.10, 2.47]) and more severe knee OA (aOR = 2.64, 95% CI = [1.59, 4.38]). Further adjustment for knee or hip injury did not appreciably change the results.

**Conclusions:** African American men and women are not spared from radiographic hip OA. African American men are more likely than Caucasian men to have hip OA, bilateral knee OA, and more severe knee OA, and these differences cannot be explained by age, body mass index, education, or joint injury differences. African American women are more likely to have knee OA, bilateral knee OA, and more severe knee OA than Caucasian women, but these differences are primarily explained by differences in body mass index.

**Further research:** Further studies of ethnic differences in individual radiographic features of knee and hip OA and radiographic patellofemoral OA are underway in this sample. In addition, associations between radiographic OA and symptoms, physical signs of OA, and functional status are also in progress. Potential explanations for the increased severity of knee OA and

bilateral knee OA in the African American men may be related to occupational physical demands, physical activity, diet, other lifestyle factors, or genetics.

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2. Anderson JJ, Felson DT. Factors associated with osteoarthritis of the knee in the first National Health and Nutrition Examination Survey (NHANESI): evidence for an association with overweight, race, and physical demands of work. *Am J Epidemiol.* 1988;128:179-89.
3. Tepper S, Hochberg MC. Factors associated with hip osteoarthritis: Data from the first National Health and Nutrition Examination Survey. *Am J Epidemiol.* 1993;137:1081-8.
4. Sowers M, Lachance L, Hochberg M, Jamadar D. Radiographically defined osteoarthritis of the hand and knee in young and middle-aged African American and Caucasian women. *Osteoarthritis and Cartilage.* 2000; 8:69-77.
5. Jordan JM, Linder GF, Renner JB, Fryer JG. The impact of arthritis in rural populations. *Arth Care & Res.* 1995;8:242-50.

## **Wound Healing and Keloids**

A. Paul Kelly, M.D.

Keloids result from the overproduction of dermal collagen during wound healing. Although a fairly common problem, there are no in-depth epidemiologic studies on patients with keloids. Our plan is to be the first investigative team to integrate cellular, molecular and genetic studies with comprehensive epidemiologic information. Our studies found that 60% of keloid patients had at least one 1st degree relative with keloids. In thirty seven percent of our patients either their father or mother had keloids; while 28% had a sister and 16% a brother with keloids. The average age of onset was 19.

To prevent the many contradictions in the keloid literature we pioneered a way to standardize keloid research with the three site method; that is studying tissue from clinically normal skin adjacent to the keloid and from the inflammatory border, stable border and central regressing areas of the keloid. Our mast cell studies indicate that each area presented a different cellular picture. Individual mast cells in the inflammatory border had an intimate relationship with a fibroblast but were not degranulated. The intimate relationship was still present in the stable border but the mast cells were degranulated. The central regressing area was similar to clinically normal skin.

Our vascular associated keloid research revealed a higher level of VEGF is produced by keloid fibroblasts verses those of normal skin. VEGF increases u-PA in normal skin microvascular endothelial cells (MECs) but does not have any effect of keloid MECs. A higher level of PAI-1 activity is observed in both keloid fibroblasts and MECs and elevation of PAI-1 activity is associated with an impaired in vitro angiogenic activity by keloid MECs.

Our keloid study model is unique because for the first time all investigations will be performed using a patient population that has undergone an extensive epidemiologic evaluation and their keloid tissue and blood will be used for molecular, cellular and genetic studies.

## Genetic Variations of Receptors for Immunoglobulin (Fc $\gamma$ R): Determinants of Severity of Systemic Lupus Erythematosus (SLE)

Jane E. Salmon, M.D.

SLE is a heterogeneous disease with a relatively higher prevalence and worse outcome in non-Caucasian populations. Genetic factors are considered major determinants of disease and may, in part, account for variations in prevalence, clinical manifestations, course, and outcome of SLE among ethnic groups. Genetically determined alterations in receptors for the Fc region of IgG (Fc $\gamma$ R) provide a possible basis for inherited susceptibility to particular SLE phenotypes. Fc $\gamma$ R provide the link between the humoral and cellular aspects of the immune cascade. Allelic variants of human Fc $\gamma$ R profoundly influence effector cell function. Single amino acid substitutions within the extracellular domains of stimulatory Fc $\gamma$ R alter the ability of the receptor to bind IgG and low binding alleles have been associated with risk for and phenotype of autoimmune and infectious disease.

Fc $\gamma$ RIIa, expressed on mononuclear phagocytes, neutrophils, and platelets, has two codominantly expressed alleles, H131 and R131, which differ at amino acid position 131 in the extracellular domain (arginine or histidine, respectively) and differ substantially in their ability to bind human IgG2. H131 is the high binding allele, R131 low binding, and heterozygotes have intermediate function. Because IgG2 is a poor activator of the classical complement pathway, Fc $\gamma$ RIIa-H131 is essential for handling IgG2 immune complexes. Fc $\gamma$ RIIIa, which is expressed on mononuclear phagocytes and natural killer cells, also has two codominantly expressed alleles, F176 and V176, which differ in one amino acid at position 176 in the extracellular domain (phenylalanine or valine, respectively). Fc $\gamma$ RIIIa alleles differ in IgG1 and IgG3 binding; V/V176 homozygotes bind IgG1 and IgG3 more efficiently than F/F176.

The interplay between the humoral immune response and Fc $\gamma$ R genotypes is a key determinant of the handling of opsonized antigens. Such antigen-antibody immune complexes are removed from the circulation by the mononuclear phagocyte system, primarily the liver and spleen. Impaired removal of immune complexes in systemic lupus erythematosus (SLE) leads to tissue deposition of immune complexes, release of inflammatory mediators, influx of inflammatory cells, and target organ damage, events crucial to nephritis.

We have shown that low binding alleles of Fc $\gamma$ R (Fc $\gamma$ RIIa-R131 and Fc $\gamma$ RIIIa-F176) are enriched in African American patients and Hispanic patients with SLE. In African Americans, a population with increased prevalence and severity of SLE, the skewing in the distribution of Fc $\gamma$ R alleles is most profound in SLE patients with nephritis. Comparison of the distribution of Fc $\gamma$ RIIa and Fc $\gamma$ RIIIa alleles in Hispanic patients, another population with high prevalence of lupus renal disease, reveals an increased the frequency of low binding alleles and a marked decrease in homozygosity for high binding alleles. There appears to be selection for the Fc $\gamma$ RIIa-R131-Fc $\gamma$ RIIIa-F176 haplotype in Hispanic patients. This suggests that low binding alleles of both Fc $\gamma$ RIIa and Fc $\gamma$ RIIIa confer risk for SLE and may act additively in the pathogenesis of disease, whereas the high binding haplotype, Fc $\gamma$ RIIa-H131-Fc $\gamma$ RIIIa-V176, is protective, particularly in the homozygous state. The high prevalence of renal disease coupled with the high frequency of low binding Fc $\gamma$ R alleles in African American and Hispanic populations suggests that these

genes may be an important determinant of susceptibility to lupus nephritis. Recognition of specific inherited disease associated genotypes expands our understanding of disease pathogenesis and may provide prognostic markers for disease severity.

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## Environmental Risk Factors for Human and Murine Lupus

Evelyn V. Hess, M.D., M.A.C.P., M.A.C.R.

There are nearly 100 autoimmune disorders and although there is a great deal of information on the mechanisms, the actual cause or causes is not yet known. Whether or not environmental factors, either infections or other agents are causal, has not yet been determined. The association of certain medications with lupus syndromes, noted first in 1945, has been of considerable interest and an important study model. There are now over 70 such medications implicated. One of the most recent to be reported is minocycline used in the treatment of acne. Most physicians are now aware of these associations and when symptoms occur, the offending drug is stopped and the symptoms clear up very quickly. These drug-related lupus syndromes can occur in men and women and in older as well as younger people. As with systemic lupus itself, some genetic associations have also been found with these drug-related syndromes.

Today, with the increasing use of very powerful biologic agents, cases of lupus and other autoimmune syndromes are being reported in association with many of the cytokine treatments such as the interferons, interleukins and more recently with the anti-tumor necrosis factor alpha used in the treatment of rheumatoid arthritis and now other conditions. There are also reports of a number of alternative compounds being associated with lupus syndromes.

There is now a great interest in the potential of environmental agents to be related to autoimmune diseases. Table 1 shows a current list of candidates. There have been two large confirmed environmental outbreaks. The first was in Spain in 1981 when over 35,000 people manifested a wide range of disorders including autoimmune disorders after the ingestion of denatured rapeseed oil. The second was eosinophilic myalgia syndrome first described in 1989, in which the muscle appeared to be a target organ with some patients also developing scleroderma, lung disease and nerve involvement, rather like the Spanish outbreak. The presumed cause was a contaminant in the L-tryptophan taken as an alternative medicine by many people.

There are a number of heavy metals that have been shown to induce autoantibodies and also renal disease, particularly in animal models. Mercury, gold and cadmium are three such agents. Recent work on pristane has also induced an interesting lupus model in mice. Infections, of course, are part of the environment and there has been considerable investigation into their potential as a cause. Viral infections, like drugs, have been related to a temporary lupus state. There is current concern about the role of immunizations, although as yet there is no hard data from any appropriate planned studies.

The Environmental Diseases Study Group of the American College of Rheumatology has worked, over the past few years, to provide an approach to documenting these clinical associations and has outlined a system for documentation and research. Table 2 shows the outline of the approach.

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**Table 1.** Environmental factors reported to be associated with the development of autoantibodies and lupus-like syndromes.

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Hydrazines  
Tartrazine  
Hair dyes  
Chemicals used in computer manufacturing  
? Trichloroethylene  
? Industrial emissions and hazardous wastes  
Silica (quartz)  
Paraffin/silicone  
Mercury  
Cadmium  
Gold  
L-canavanine  
Rapeseed oil (toxic oil syndrome)  
L-tryptophan, eosinophilia myalgia syndrome

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**Table 2.** Proposed stages for the identification and definition of environmentally associated rheumatic disorders.

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*Stage 1:* *Proposing the association.* Case reports or case series, defined by certain conditions, suggest the possible association of a clinical disorder with an environmental exposure.

*Stage 2:* *Testing the association.* Epidemiologic, clinical and laboratory studies test the hypothesis that the exposure is associated with the disorder.

*Stage 3:* *Defining the disorder.* If the approaches in stage 2 support an association, classification and other criteria are developed.

*Stage 4:* *Refining the disorder.* An ongoing reassessment and revision of classification and other criteria are performed in light of additional clinical and laboratory information.

## Risk Factors for Systemic Lupus Erythematosus in the Carolina Lupus Study: Does Anything Explain the Racial Disparity in Disease?

Glinda S. Cooper, Ph.D.

**Background:** The incidence and prevalence of systemic lupus erythematosus (SLE) are at least 3 times higher in African Americans compared with whites but reasons for this racial disparity are not clear. The role of genetics in SLE has been extensively studied but relatively little is known about other influences on disease. At least 85% of SLE patients are female. Experimental studies in mice demonstrate disease exacerbation by estrogen and prolactin and amelioration by androgens.

**Methods:** We examined markers of endogenous exposures of estrogen and prolactin, exposures potentially related to microchimerism (pre-eclampsia, transfusions), and other aspects of medical and occupational history in relation to risk of developing SLE in a population-based case-control study. SLE patients (n=265) diagnosed between January 1, 1995 and July 31, 1999 were recruited through university and community-based rheumatology practices in 60 contiguous counties in North Carolina and South Carolina. Controls (n=355) were identified through driver's license records and were frequency matched to patients by age, sex, and state. Data collection included a structured in-person interview.

**Results:** There was no association between most markers of estrogen exposure (e.g., age at menarche, use of hormone replacement therapy) and risk of developing SLE. However, other reproductive, medical, and occupational exposures were associated with disease risk (see table next page).

Race-specific analyses allowed us to examine whether the racial disparity in disease risk could be explained by differences in risk factors. Except for transfusions, any exposure associated with risk of SLE in African Americans was also associated with risk in whites, and the differences in associations between races were not statistically significant. The transfusion results could be due to a low prevalence of transfusions among African American controls. The increased risk experienced by African Americans could not be explained by an increased prevalence of the specific risk factors we examined (data not shown). Since breast-feeding is a potentially modifiable factor and is less common among African Americans, it is important to confirm the protective effect we observed in our study.

Significant Associations	Total Sample		African Americans		Whites:	
	OR	95% CI	OR	95% CI	OR	95% CI
Ever breastfed	0.6	0.4, 0.9	0.7	0.4, 1.4	0.5	0.3, 1.0
Pre-eclampsia	3.7	1.2, 11.0	2.5	0.5, 13.1	3.8	0.8, 16.2
Transfusions	1.0	0.6, 1.8	3.8	1.0, 14.0	0.7	0.3, 1.5
Medication allergy	3.1	2.1, 4.5	3.6	1.9, 7.0	3.3	1.9, 5.6
Herpes zoster	2.5	1.1, 5.9	5.4	0.6, 47	2.2	0.8, 6.4
Stroke, blood clot, pulmonary embolism	5.4	2.0, 15	5.9	0.7, 51	7.2	2.1, 25
Silica dust	3.2	1.4, 7.7	5.2	1.2, 22.4	2.3	0.7, 7.3

\* Logistic regression adjusting for age, race, education, state (and sex).

## **Genetic and Environmental Risk Factors for Lupus and Other Connective Tissue Diseases (CTDs)**

Patricia A. Fraser, M.D., M.P.H., M.S.

Association and linkage studies have shown that multiple genes appear to modulate either the risk of lupus or a specific lupus phenotype. Of the genes identified to date, most do not explain the excess risk of SLE observed among African Americans, nor do they account for the more severe lupus phenotypes that predominate in this and other racial and ethnic groups in the U. S. Currently, environmental risk factors for lupus and other connective tissue diseases (CTDs) are the subjects of intense study in several regions. The mechanisms for these environmental triggers of SLE are uncertain. In particular, the role of inherited susceptibility to environmentally induced genotoxicity in SLE and other CTD is not well defined. Further investigation of gene-environment interactions may elucidate the etiology of differential risk and disease expression in U.S. populations.

## Ethnic Differences in Cartilage Oligomeric Matrix Protein (COMP) and Its Association with Osteoarthritis: The Johnston County Osteoarthritis Project

Joanne M. Jordan, M.D., M.P.H.

Cartilage oligomeric matrix protein (COMP) is a 524kD glycoprotein found in cartilage, tendon, and synovium(1-3). It has been reported to be predictive of progression of knee osteoarthritis (OA) (4) and to be associated with knee OA severity, bilateral knee OA, and the number of joints with OA(5,6). To date, studies of serum COMP and osteoarthritis have only been performed in Caucasians. We report the first large, population-based study of ethnic differences in serum COMP and its relationship to OA in African Americans and Caucasians.

**Methods:** Approximately equal numbers of cases of radiographic knee OA (Kellgren-Lawrence [K-L] grade  $\geq 2$ ) and controls (K-L grade 0 in all knees and hips) were randomly selected with frequency matching by ethnic group, gender, and agegroup (45-54, 55-64,  $\geq 65$  years) from the Johnston County Osteoarthritis Project, a population-based prospective cohort of osteoarthritis in African Americans and Caucasians in North Carolina. Sera were analyzed by ELISA with monoclonal antibody 17-C10. Associations between serum ln COMP and OA were examined for each ethnic group with general linear models separately for the following OA variables: a) knee OA defined as K-L grade  $\geq 2$ , b) severe knee OA defined as K-L grades  $\geq 3$ ; c) bilateral knee OA; d) knee + hip OA; e) number of knees and hips with OA. Potential confounders included agegroup, gender, and body mass index (BMI).

**Results:** 268 African American and 291 Caucasian samples were selected. Mean age was  $60.8 \pm 10.3$  years. Mean COMP was  $1500 \pm 550.8$  ng/ml in the African Americans and  $1133.9 \pm 437.5$  ng/ml in the Caucasians, ( $p = 0.0001$ ); after adjustment, this ethnic difference remained highly statistically significant ( $p = 0.0001$ ).

In analyses stratified by ethnic group, ln COMP was positively associated with agegroup, ( $p = 0.0001$ ) and with each measure of OA, ( $p < 0.009$ ), but not gender; ln COMP was associated with BMI only in African Americans, ( $p = 0.01$ ). In adjusted models, ln COMP remained significantly associated with agegroup in both ethnic groups, ( $p = 0.0001$ ). However, associations between ln COMP and each OA measure remained statistically significant in Caucasians only ( $p \leq 0.004$ ), but not in African Americans. ln COMP remained significantly associated with BMI in African Americans, ( $p \leq 0.01$ ), but not in Caucasians.

**Conclusions:** The strength of associations between COMP and OA status varied by ethnic group, with stronger associations noted in Caucasians. BMI was associated with COMP in African Americans only. COMP may be more useful as a marker of OA in Caucasians than in African Americans.

**Future research:** These results suggest possible genetic differences in determinants of serum COMP in African Americans and Caucasians. Future studies to explain these findings could include assessment of COMP genes in the two ethnic groups and examination of burden of OA in other joint groups beyond knees and hips.

BMI in this context could be viewed as either an environmental factor interacting with the genetic or as an interaction between two (or more) genetic factors, since genetics may also influence BMI. Further exploration of the BMI:COMP relationship in African Americans could be done by examining associations between COMP and body composition, height, weight, weight at age 18 years as an indicator of life-long obesity, and bone mineral density. Other factors that might explain the stronger association of serum COMP with BMI in African Americans and weaker associations with knee and hip OA than seen in Caucasians, might include differences in COMP clearance from the joints and differences in sources of COMP in the body. Further studies of ethnic differences in other OA biomarkers, including CRP, keratan sulfate, and hyaluronic acid in this sample, are underway.

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## Physician/Patient Satisfaction With Cross-Cultural Clinical Encounters

JudyAnn Bigby, M.D. and June Cooper, M.S.W.

**Background:** Despite more than two decades of reports describing racial and ethnic disparities in health status and access to health care the reasons for disparities remain poorly understood. In Boston for example, black babies die within the first year of life at a higher rate compared to white infants. In 1998 for example, the black infant mortality rate was 10.4 (deaths per 1,000 live births) compared to 4.0 for white infants. As part of the effort to better understand factors contributing to disparities in infant mortality in Boston, the Boston Public Health Commission conducts reviews of infant deaths. In the past, these reviews included extensive personal interviews with women experiencing an infant death. In these interview women of color described lack of connection to their health care providers [1] as an important factor in their health care experience. Lack of connection to and dissatisfaction with providers are consistent with national survey results demonstrating that persons from racial and ethnic minority groups are less likely than whites to be satisfied with the quality of their health care [2].

Recent reports suggest that physician behavior in the doctor-patient interaction and decision making about procedures and diagnostic tests may contribute to health disparities[3,4]. It is not surprising that physician behavior may contribute to health inequities given the medical profession's history of racial segregation, bias, and exclusion of blacks and other minorities from medical schools and medical organizations. In addition, the medical profession reflects the deficits in the larger society.

Ethical self-awareness is necessary to understand how one's own values as a "physician-person" shape medical encounters. Critical self-reflection is an important component of professionalism in the medical setting because physician behaviors that are biased and judgmental are often unintentional and subtle, in contrast to those that are overtly racist. Appropriate professional behavior, therefore, acknowledges that emotional responses in physicians influence clinical behavior and that strong affective reactions can undermine professional behavior when the patient is different than the physician in terms of racial or ethnic identity. Understanding this dynamic allows physicians to consciously address it. When physicians do not acknowledge or understand this behavior it can lead to health disparities if it influences treatment decisions or when the patient perceives disrespect, lack of empathy, or lack of compassion.

**Goals:** The Physician/Patient Satisfaction with Cross Cultural Clinical Encounters project was initially designed to better understand factors that contribute to black/white disparities in infant mortality in Boston. The goals of this project are to:

- To better understand how women of color experience personal interactions with physicians from a racial, ethnic, cultural, and class point of view;
- To better understand physicians' perceptions of how racial/ethnic identity and class impact the care of women;
- To identify common domains of quality of care, including satisfaction, among physicians and patients as they relate to personal differences between the provider and women;
- To develop guidelines for satisfaction in the cross cultural provider/patient interaction when the patient is a woman of color.

**Methods:** In order to better understand, the racial/ethnic/cultural aspects of the physician/patient interaction we are collaborating with a Working Group of white physicians and women of color from the Boston community. During Phase I we have conducted audiotaped interviews with members of the Working Group to assess how they view the cross cultural/racial/ethnic interaction. The major themes from these interviews were identified based on reviews by independent readers of the interviews and qualitative analysis. The Working Group participates in facilitated discussions about the themes from these interviews, reviews of taped interactions between patients and doctors, and general discussions about how race impacts health care and health. In Phase II we will explore the themes that emerge from the Working Group by conducting focus groups with patients and physicians. We will use the results from the focus groups to develop a tool to assess the satisfaction with racial and ethnic aspects of interactions. During Phase III we will field-test the satisfaction tool. We will use these results to develop guidelines for achieving satisfaction in the cross cultural encounter.

During the Health Disparities in Arthritis and Musculoskeletal and Skin Diseases conference I will report on Phase I of this project. I will present a model for understanding how personal attitudes and beliefs influence the provider/patient interaction. I will also describe physicians' and patients' perceptions of how race impacts communication and trust in relationships.

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## Ethnic Differences in the Management of Osteoarthritis

C.K. Kwoh, M.D.; S.A. Ibrahim, M.D., M.P.H.; C.J. Burant, M.A; and L.A. Siminoff, Ph.D.

**Study objective:** This study used the VA patient population to examine patient factors that distinguish AA and white patients who are potential candidates for joint replacement.

### Methods/measurements:

**Study sample:** Patients were recruited from the Louis Stokes Cleveland DVAMC during routine visits to primary care clinics, 600 (44% AA; 56% white) patients were enrolled. To be eligible, patients had to be 50 years of age or older. Knee or hip pain had to be chronic in nature (at least six months<sup>1</sup> duration) and to be at least moderate in severity (based on the Lequense scale). Patients who had a joint replacement in the past were excluded.

All study participants underwent knee or hip x-rays. Structured survey instruments were utilized to examine study objectives.

**Analysis:** We performed baseline comparisons using the Chi-square test for categorical variables and T-test for continuous, normally-distributed variables. We used logistic regression models to examine demographic, clinical, and psychosocial covariates. Covariates in the final models were: age; educational level; income; religiosity score; Charlson index; WOMAC score; Religiosity score; Geriatric Depression score.

### Results:

**Baseline characteristics:** AA and white patients in this cohort were comparable with respect to age ( $66 \pm 10$  vs.  $66 \pm 9$ ,  $p = 0.60$ ), severity of arthritis [measured by Lequesne scale (mean score  $11 \pm 4$  vs.  $11 \pm 4$ ,  $p = 0.22$ )], WOMAC scale (mean score  $46 \pm 17$  vs.  $45 \pm 17$ ,  $p = 0.32$ ), Charlson comorbidity index ( $2.3 \pm 2$  vs  $2.5 \pm 2$ ,  $P = 0.24$ ), and Geriatric Depression scale ( $4.5 \pm 3.4$  vs.  $5 \pm 3.8$ ,  $p = 0.07$ ).

However, AA were less likely to be employed (8% vs. 15%,  $p=0.017$ ) or to be married (39% vs. 56%,  $p = 0.000$ ), but were more likely to report an annual household income of less than \$10,000 (41% vs 20%,  $p = 0.000$ ) and less than high school education (43% vs. 29%,  $p = 0.001$ ). They were also more likely to score higher on the religiosity scale ( $77 \pm 17$  vs.  $70 \pm 21$ ,  $p = 0.000$ ).

**Awareness of JR:** AAs were less likely than whites to have ever heard of joint replacement (81% vs 87%,  $p = 0.024$ ), to have had family or friends who have had joint replacement (52% vs 78%,  $p = 0.000$ ), or to have a good understanding of joint replacement as a form of treatment (44% vs. 61%,  $p = 0.000$ ).

**Perceptions on risks and benefits:** When asked " how often do they think one dies from replacement surgery," AA were more likely than whites to say "sometimes or often," but this difference was not statistically significant (25% vs. 20%,  $p = 0.119$ ). They were more likely than

whites to perceive the hospital course for surgery as lasting more than 2 weeks (45% vs 18%,  $p = 0.000$ ). Furthermore, AAs were more likely than whites to expect moderate or extreme pain (62% vs. 42%,  $p = 0.000$ ) and moderate to extreme difficulty walking (64% vs 39%,  $p = 0.000$ ) following joint replacement.

Awareness of JR:

- 1."Ever heard of joint replacement"- Adjusted OR= 0.64, 95% CI 0.37 to 1.09.
- 2."Family or friends with replacement surgery"- Adjusted OR =0.39, 95% CI 0.26 to 0.61.
- 3."Good understanding of replacement therapy"- Adjusted OR = 0.62, 95% CI 0.42 to 0.92.

Perceptions on risks/benefits questions:

1. " How often one dies from replacement surgery "- Adjusted OR = 1.24, 95% CI 0.80 to 1.93.
2. " Hospital course greater than 2 weeks"- Adjusted OR= 1.37, 95% CI 0.851 to 2.21.
3. " Moderate or extreme pain after surgery"- Adjusted OR = 2.61, 95% CI 1.74 to 3.89.
4. " Moderate or extreme difficulty walking after surgery"- Adjusted OR = 2.76, 95% CI 1.83 to 4.16.

AA were more likely than whites to perceive prayer as helpful for their arthritis (87% vs. 74%,  $p = 0.0001$ , adjusted OR 1.93, 95% CI 1.19 to 3.14). AA were also more likely than whites to have actually used prayer for their arthritis (75% vs. 56%,  $p = 0.0001$ ). In contrast, AA were less likely than whites to perceive knee/hip replacement as very helpful for their arthritis (37% vs. 60%,  $p = 0.0001$ , adjusted OR 0.52; 95% CI 0.28 to 0.98). In addition, and less likely to consider knee/hip replacement as a treatment option for their arthritis (81% vs. 89%,  $p = 0.006$ , adjusted OR 0.56 (95% CI, 0.34 to 0.94). Usefulness of prayer was examined as a potential mediating factor between ethnicity and consideration of joint replacement. When usefulness of prayer was added to the analysis, the previously significant relationship between ethnicity and consideration of joint replacement was eliminated (from a standardized beta of -0.091,  $p = 0.047$  to a standardized beta of -0.059,  $p = 0.218$ ).

**Conclusion:** In this study of male, elderly veterans with moderate to severe knee/hip osteoarthritis, African American and white patients differ significantly with respect to important aspects of their awareness and understanding of joint replacement and their perceptions of risks/benefits. In addition, African Americans were more likely than whites to perceive prayer as very helpful for their arthritis, while they were less likely than whites to perceive joint replacement as very helpful for their arthritis patients. Furthermore, African Americans were less likely than whites to consider knee/hip replacement as a treatment option for their arthritis with perception of the usefulness of prayer as a potential mediator variable. These differences may partially explain the observed racial variation in the utilization of joint replacement for knee/hip osteoarthritis.

## Race and Its Relationship to Prevalence, Care-Seeking and Care Patterns in Low Back Pain

Tim Carey, M.D., M.P.H., and Joanne Garrett, Ph.D.

Low back pain (LBP) is a common problem and a cause of substantial morbidity and time off work. Little research to date has examined the relationship of patient race to back pain prevalence or care seeking. We present several analyses from a prevalence survey of back pain conducted in North Carolina in 1993 and a cohort study of 1574 acute low back pain patients seeking care from a variety of randomly selected North Carolina (NC) providers in the mid-1990's: primary care MD's; Doctors of Chiropractic (DC's), Orthopedic surgeons, and primary care providers at a group model HMO.

We conducted a prevalence survey using random-digit dialing methods, and a structured interview to over 4,000 NC households containing 8067 individuals. Acute low back pain (episode lasting less than 3 months but severe enough to impair usual daily activities) occurred in the previous year in 8.3% (95% CI: 7.3; 9.3) of whites, but 5.2% (3.8; 6.6) of blacks ( $p<0.01$ ). A similar pattern was found for chronic back pain in the previous year: 4.1% (3.4; 4.7) in whites and 3.0% (2.0; 4.0) in blacks ( $p=0.07$ ). However, in blacks who did have back pain, care seeking was more common than in whites who had low back pain: 59% vs 36%,  $p<0.01$ , also reporting higher pain scores and more time off work for acute back pain.

Our cohort study was conducted prospectively, enrolling patients on presentation to the providers' offices and contacting patients by telephone at baseline, 2, 4, 8, 12 and 24 weeks, as well as 22 months after the initial visit. Blacks at baseline had higher pain scores (5.92 vs 5.25,  $p<0.01$  on a 10 point scale) and functional disability (12.1 vs 11,  $p=0.01$  as assessed by the 23 item Roland-Morris scale), yet were considered by the health care provider as having less severe pain and less likely to have disc disease compared with white patients (all comparisons  $p<0.01$ ). While blacks and whites had similar times to self-assessed recovery, blacks had greater functional disability at most follow-up interviews. Blacks were significantly less likely to receive radiographs (49 vs 40%) or advanced imaging studies (10 vs 6%) even after controlling for income, education, baseline severity of LBP and insurance status ( $p<0.05$ ). DC's had different practice approaches from MD's, which appeared to interact with patient race.

The relationship of patient race to the prevalence and course of LBP is complex, with differences in prevalence and care patterns. Blacks receive less intense diagnostic and treatment courses when compared with whites, although severity of impairment is at least as great.

## **Racial Differences in Pain, Physical Disability, Psychological Disability, and Coping in Osteoarthritis (OA)**

Christopher L. Edwards, Ph.D.

The overall aim of this presentation is: 1) to examine racial differences in pain, physical disability, psychological disability, and coping in persons having OA pain, 2) and to examine if race and coping are important factors in explaining the relationship between OA pain and disability. Although there is some literature on differences in pain coping and disability as a function of race, to date very few studies in the OA literature have examined the mechanism of these differences. Information on the mechanisms of racial differences are potentially important in understanding reports of OA pain and disability. More specifically, the development of new interventions that better address race-related differences in OA pain and pain coping are highly dependent upon have an adequate understanding of the mechanisms of pain and coping in both populations. Further, given the prevalence of OA and other arthritic conditions in African Americans, it is especially important to understand how African Americans differ in OA pain and disability from Caucasians and to determine whether coping style is important in understanding these differences.

## Ethnicity, Self-Management, and Self-Efficacy

Kate Lorig R.N., Dr.P.H.

There is a long history of behavioral interventions for people with arthritis. The first published studies appeared in the 1970s. Since that time there have been more than 125 published studies. Nevertheless, there has been little attention to behavioral interventions across ethnic groups.

The studies of the Arthritis Self-Management Program (ASMP) began in the 1980s. This 12-hour, community-based, peer-led arthritis program has been found, in randomized trials, to increase healthful behaviors, improve health status and self-efficacy in English speaking largely Caucasian populations.[1-2] Furthermore, there is evidence that changes in self-efficacy are related to changes in health status and that self-efficacy is at least one of the mechanisms responsible for the program's positive outcomes.[3] Finally, it has been demonstrated that after four years ASMP participants continue to have less pain and reduced outpatient visits.[4] Based on this data the ASMP is considered a cost-effective intervention.

More recently the ASMP has been evaluated on other populations. For Spanish-speakers, the program was revised to be culturally relevant. In a randomized four-month trial for approximately 300 subjects the outcomes were found to be similar to those found with the original studies. In addition, the four-month benefits of the program were sustained for one year. Again self-efficacy was found to be a key mechanism with self-efficacy changes over four months predicting one-year outcomes.[5]

A small study in Hong Kong as well as a study with First Nations People in Canada suggest that the Arthritis Self-Management Program is beneficial for these populations and that again self-efficacy may be a key mechanism.[6]

Finally, in the past year or so two more studies demonstrated similar outcomes to the original ASMP study. One of these was a longitudinal study in Australia for all the people in the country (N approximately 400) who took the ASMP during a four-month period. Data collected at four months were similar to the original ASMP study and two-year data are currently being collected. The second study was conducted in Great Britain.[7]

Unfortunately, we do not have strong ASMP studies in other populations such as African Americans, Native Americans or Asians, except for the small study conducted in Hong Kong. Nevertheless, it appears that the concepts of self-management if made culturally relevant are appropriate for many cultures and that self-efficacy is at least one behavioral mechanism, which has relevance across cultures.

As for most behavioral interventions, there is a great need for randomized trials across ethnic groups. Even more important is the need for dissemination studies to determine how best to close the disparities in the availability of arthritis behavioral interventions across ethnic groups.

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## Complementary and Alternative Medicine Use in Different Ethnic Groups

Leigh F. Callahan, Ph.D.

Complementary and alternative medicine (CAM) practices, functionally defined as medical interventions not widely taught at US medical schools nor generally available at US hospitals, continue to attract increased national attention from the public, media, medical community, and governmental agencies. CAM use and expenditures increased substantially between 1990 and 1997. The reasons underlying CAM's popularity are unclear and may somewhat depend on the purpose of the CAM use. Reasons cited for using CAM include: 1) dissatisfaction with conventional treatment because it has been ineffective, has produced adverse affects, or is seen as impersonal and costly; 2) perceptions that CAM provides more personal control and autonomy over health care decisions; 3) beliefs that CAM therapies are seen as more compatible with patients' values, worldview; and 4) beliefs regarding the nature and meaning of health and illness.

Studies examining CAM use in different ethnic groups of patients with arthritis are limited to date. The ethnic groups that have been compared in the literature include African-Americans, Hispanics, and Caucasians. Some studies have compared all three groups and others have examined only two of the groups, or examined racial minorities versus Caucasians. Also, some studies have adjusted for other potential determinants of CAM use, such as gender, education level, age, and disease activity. In the limited reports, ethnic group differences have been noted for some CAM practices. African-American and Hispanic groups were more likely to report using religion, including prayer or attending church services. Herbs, usually in infused teas, and vitamins and nutritional supplements were most commonly used in both African-American and Hispanic Groups. Racial minorities were significantly more likely to use rubs and lotions and apple cider vinegar. And, African-Americans were less likely to use rest, positive thinking, heat, and conventional therapies such as prescription drugs and over-the-counter medications.

Current research suggests that perceived need, rather than severity of illness, is the most influential factor in explaining a significant proportion of the variation in health behaviors and health services utilization. Primary factors that influence perceived need include: 1) the capacity to assess what is wrong; 2) the ability to self-manage the problem; 3) self-efficacy; and 4) knowledge of the risks and benefits of medical care. Secondary factors that influence the primary factors are information, education, ethnicity, culture, social support, comorbidity, and the attitudes of health care providers. It is important to understand the links and associations between these factors. Ethnicity is a variable needing considerable clarification.

## **Addressing Barriers to Care in a Culturally Diverse Indigent Population: The Los Angeles County Rheumatoid Arthritis Health Project**

Andrew L. Wong, M.D., F.A.C.P., F.A.C.R., Brian S. Mittman, Janet Aiso,  
Victoria P. Lau, Judith O. Harker

**Purpose:** To describe the foundation, design and initial results of a multi-disciplinary and multi-faceted program of research, education and quality enhancement activities designed to improve healthcare processes and outcomes for rheumatoid arthritis (RA) patients within the 3 million culturally diverse, largely indigent patient population served by the Los Angeles County Department of Health Services (LAC-DHS).

**Background:** RA is a chronic inflammatory disease leading to substantial disability and health care expenditures among patients not receiving timely, appropriate medical treatment. Indigent patients with chronic conditions served by public healthcare systems and patients having language and cultural barriers to accessing care may likely be at greater risk of not receiving timely, appropriate care for a chronic disease such as RA than patients with private medical insurance or Medicare not facing such barriers. The LAC-DHS healthcare delivery system now comprises a mix of public and contracted private outpatient clinics and a network of 6 public tertiary care hospitals. All rheumatology specialty services for the approximately 3 million patients served by LAC-DHS are provided by the rheumatology divisions at 4 of the public hospitals. The four LAC DHS Rheumatology divisions are collaborating in a program of activities designed to improve patient and healthcare delivery system performance, knowledge and behaviors related to RA care. Together, the activities are identifying and reducing barriers to access and care resulting in more appropriate and culturally effective RA management and treatment practices.

**Method:** The RA Health Project includes research activities (an outcomes study and patient registry targeting all LAC-DHS RA patients), healthcare delivery system quality enhancement activities (improvements in drug formulary policies accompanied by policy decision-support outcomes analyses, consensus meetings to discuss and improve clinical policies and practices) and patient outreach and empowerment programs. Initial quality enhancement and policy decision-support activities have focused on clinical policy development and formulary enhancements targeting new FDA approved but costly RA medical therapies (new DMARDs and COX-2 inhibitors). Patient self help and empowerment activities have included patient education, exercise classes, support groups, and the implementation and dissemination of the "Spanish Arthritis Empowerment Program", which is successfully meeting the needs of Spanish speaking arthritis patients in several under-served communities of Los Angeles and Orange Counties in Southern California. The initial LAC DHS Outcomes Study of New Treatments for RA enrolled over 170 RA patients (Spanish and English speaking) during March through August 2000, collecting patient questionnaire baseline and follow-up social, demographic, disease activity, treatment and outcomes data, and extracting demographic and medical service utilization data from the computerized administrative/encounter database systems. Initial evaluation of the LAC Olive View-UCLA Medical Center Spanish Arthritis Empowerment Program was performed on 267 arthritis patients enrolled in May to Nov. 1997 and 225 patients enrolled in May to Nov. 1998. Effective dissemination of this program as the Arthritis

Foundation's Orange County Spanish Arthritis Empowerment Program is preliminarily being evaluated on 162 patients enrolled in under-served communities in Orange County between Oct. 1999 to Sept. 2000. Written pre-tests were completed on the first day of the course, and post-tests were completed on the last day of the six-week course and 4 month later. These Spanish-language instruments collected demographic information and measures of pain, self-report joint counts, function (HAQ), arthritis knowledge, self-efficacy in dealing with symptoms, and program satisfaction.

**Results:** Policy and consensus development activities resulted in enhancements to the LAC DHS Central Formulary through the addition of a provisional "outcomes conditional" classification and development of a consensus-based guideline addressing use of three newly FDA approved medications for treatment of RA. Outcomes study data are currently under analysis to assess health outcome and service utilization impacts of these policy and quality enhancement activities. 54% of completed baseline questionnaires were completed in English, with the remaining 46% in Spanish. 14% of patients reported RA disease duration of 3 years of less, with 86% reporting 4 or more years. Over 83% of the patients reported their general health as "poor" or "average," vs. "good," "very good" or "excellent." 55% of respondents reported an educational level less than high school graduate, with 22% reporting high school graduate and 23% some college or greater. Fewer than 10% of the patients reported that they are "working full-time." Evaluation of the Olive View-UCLA Medical Center Spanish Arthritis Empowerment Program has shown significant improvements of study participants enrolled in 1997 and 1998: mean age of participants was  $46.4 \pm 15.1$  yrs. 78.7% were born in Mexico, 13.5% in Central America, 3.7% in South America and 3.3% in the US. 54% had 6th grade education or less. 63.3% spoke only Spanish. 51.2% were housewives, 19.1% were employed full or part-time. 58% had no medical insurance. Paired t-tests showed significant pre-post improvement in: pain VAS rating, self-efficacy in dealing with pain and other symptoms, general health, and medical/empowerment knowledge of arthritis (all at  $p < .01$ ). As expected, there was no significant deterioration noted in function (HAQ), or numbers of swollen or painful joints. Participant comments indicated high satisfaction. Findings from other implementation of this program (e.g., at Stanford University and within under-served communities in Orange County by the Arthritis Foundation) were similar.

**Conclusion:** Addressing barriers to care for chronic medical conditions, such as RA, cared by culturally diverse or under-insured patient populations requires a coordinated multi-disciplinary and multi-faceted program of activities. The research, policy and system- and patient-targeted quality enhancement and educational/empowerment activities comprising the Los Angeles County RA Health Project represents an effort to implement and operationalize this approach, with initial indications of success.

## Understanding Disparities In Ethnic Populations

Ana F. Abraido-Lanza, Ph.D.

There is a lack of adequate data on arthritis among ethnic minority populations in the United States. This paper will present basic data on demographic and health profile characteristics of various ethnic minority populations in the U.S. The main thesis of the paper is that, in order to understand and address health disparities, a broad approach is needed, integrating the behavioral, social and biomedical sciences. Examples will draw primarily from research on Latino populations. Latinos comprise over 9% of the U.S. population, and by the year 2020, Latinos will constitute the largest minority group in the U.S. Arthritis ranked second as the leading cause of activity limitation among Latinos (Hispanics) in a recent national survey. Furthermore, among Latinos, the prevalence rate and proportion of persons with activity limitations are projected to increase markedly by 2020 due to increases in the average age of this population. Yet, there is a great gap in knowledge concerning socioeconomic and other factors related to the health of Latinos with facing chronic illnesses such as arthritis. A large body of evidence indicates that low socioeconomic status (SES) is associated with greater morbidity of many diseases, including osteoarthritis and rheumatoid arthritis. Although Latinos are a heterogeneous population, as a group, Latinos have a worse SES profile than non-Latino whites. Despite this disadvantage, Latinos have a lower arthritis prevalence rate than non-Latino whites. Among persons with arthritis, however, Latinos report more disability than non-Latino whites. Reasons for these differences are unknown, but may include disparities in sociodemographic factors, social capital, access to health care, and acculturation factors. Therefore, in order to address disparities, attention must be placed on these various factors.

## Strategies to Eliminate Disparities – the Research Agenda Literacy Programs

Lawren H. Daltroy, Dr.P.H.

### 1. Background:

*Literacy.* indicates the ability to read, and *functional literacy* focuses on people's ability to use the written word for everyday tasks. However, reading is part of a more complex phenomenon, which is ability to use language to organize the world and take action. As people develop literacy, they develop a number of other skills, including reading for meaning (vs. decoding of individual words), ability to describe with accuracy, ability to give and understand instructions without relying on face-to-face interaction and shared context, a large working vocabulary, and understanding of abstract concepts.

*Prevalence of low literacy.* In 1992, a national survey of 26,000 US adults established that 90 to 94 million persons (47% to 51% of the population) have limited or extremely low functional literacy skills (1) – trouble following written instructions, locating data, using maps, understanding numbers in text, and filling out forms. The prevalence of low literacy is highest within groups with health disparities, including the elderly, the poor, and minorities (1). Widespread deficits in functional health literacy have been documented in medical patients using the Test of Functional Health Literacy in Adults (TOFHLA) (2; 3), which includes comprehension of medical directions, prescription labels, and consent forms.

*Impact on health.* Patients with low literacy report poorer health than do patients with high literacy (4). They are less likely to make use of screening (5), are more likely to present in later stages of disease (6,2) and are more likely to be hospitalized (3). Numerous studies (6,7) show that low literacy has been associated with poor health, poor understanding of treatment, greater use of health services, and low adherence to treatment regimens.

*Patient education.* Most patient education materials are written at the 11<sup>th</sup> grade or higher (8), whereas the average reading level of clinic populations and the general public is below the 8<sup>th</sup> grade level. Caregivers rarely evaluate patient literacy levels, and underestimate the proportion of patients in their practices with low levels of literacy, in part due to ignorance of the extent of the problem, and in part due to these patients' efforts to hide it out of shame (9).

Plain English materials (5<sup>th</sup> to 8<sup>th</sup> grade level) and materials with illustrations are preferred by most readers, including highly educated ones, and improve comprehension (11-15). However, the effects of low literacy materials on behaviors and health are virtually unstudied. Better educated patients may be most likely to benefit from Plain English materials (15), as low literacy patients may be unable to read at all, or may lack a vocabulary and conceptual basis for understanding what they read.

Many people, even those who can read, rely on non-written means to obtain health information. Meade and Byrd (16) found that 97% of those older than 65 years reported that television was a

principal source of health information, regardless of literacy level. Even when information is presented orally, poor readers may be poor listeners, having difficulty with unfamiliar vocabulary and decoding visual and oral information (17,18).

One study of illiterate and low literate patients (19) found that the main areas of literacy demands were navigating the health institution, completing forms, interacting with health care providers, and understanding appointment slips. Patients with low literacy rely heavily on oral explanations, visual clues, and demonstrations of tasks to learn material. Most also use a friend or family member as a surrogate reader. Thus, commonly recommended strategies for delivering health information to people with limited literacy include the use of non-written means of communication, the development of special materials for low literacy populations and readability assessment (20-22). Suggested strategies for physicians conducting individual interviews include: speak in a simpler language, repeat instructions, demonstrate key points, and avoid too many directives; combine easy-to-read written patient instructions with oral instruction; and include family members (23).

## 2. Research directions:

*Literature to date.* The American Medical Association's Ad Hoc Committee on Health Literacy (8) identified only 217 relevant articles through 1998, almost all of which were published in the 1990s (6,7). Most (162 of 217) were dedicated to establishing the epidemiology of illiteracy, readability of patient education materials, or associations between literacy and health; 38 discussed how to communicate with low-literacy populations. Only 17 discussed development or implementation of interventions to improve patients' knowledge or outcomes, of which only one was a randomized, controlled trial.

*Gaps identified.* The AMA's Council of Scientific Affairs (8) has recommended that: "Future research should focus on optimal methods of screening patients to identify those with poor health literacy, effective health education techniques, outcomes and costs associated with poor health literacy, and the causal pathway of how poor health literacy influences health." Similarly, The National Work Group on Literacy and Health (20) has concluded that "Research is needed to clarify the mechanisms through which illiteracy influences health status and health services utilization, and to determine if using low-literacy health education materials improves health outcomes."

*Methodology available.* Efforts to move forward require rigorous measurement tools and the ability to collect valid information from subjects with low or limited literacy skills. Health literacy evaluation tools are now available, particularly the Rapid Assessment of Adult Literacy in Medicine (REALM) (24) and the Test of Functional Health Literacy in Adults (TOFHLA) (2). These instruments are acceptable to patients, and are reliable and valid (25). Sullivan et al (26) have shown that valid and reliable health information can be collected from low-income, minority-group subjects who have difficulty reading, when they are offered the alternative formats of interview or self-administer with assistance.

### 3. Literacy and arthritis:

*Health status, health services utilization and work disability.* Whites and African Americans have similar rates of arthritis, but African Americans have greater rates of activity limitation, and lower rates of total joint replacement (27). Years of formal education is correlated with literacy level, although a large proportion of adults read several grade levels below their years of schooling. Lower education and literacy levels tend to cluster among members of minority groups, the poor, and immigrants. In arthritis, activity limitations are seen in 34% of those with less than high school education vs. 26% of those with at least some college (27, table 2.3). Among those with arthritis of employable age, only 47% of those with less than high school education were employed, vs. 65% of high school graduates and 78% of those with some college (27, Table 2.6). Arthritis patients with poor literacy skills may have less job flexibility, which has been associated with work disability (28).

Recent research indicates that African Americans and Hispanics are more likely than Caucasians to endorse the nihilistic beliefs that there is nothing you, or a doctor, can do for arthritis (29). African Americans were significantly more likely to believe that people with arthritis should not exercise, and Hispanics were more likely to reject the idea that seeing a doctor early could help arthritis. Such beliefs may be less amenable to public health education campaigns among populations with high levels of illiteracy, which tend to be minority and poor.

*Challenges in arthritis management.* Systemic rheumatic diseases, such as rheumatoid arthritis and systemic lupus erythematosus, place considerable demands on patients. Management of many arthritis treatment schedules challenges even literate patients, who are able to supplement doctors' instructions with written materials and reminder schedules. For patients who have trouble even reading the names of their medications or an appointment slip, it may be overwhelming.

Literacy may be an important mediating variable that can help to explain many difficulties that arthritis disease patients have in self-management. Literacy may affect management, and thus patient outcomes, via the following hypothesized pathways, which can be the focus of research:

- Quantity and quality of communication between patient and doctor/providers (Low literacy patients may lack vocabulary to describe symptoms/history accurately, to negotiate with the doctor and make decisions about treatments, or to understand instructions, concepts, and medical descriptions of disease processes. Patients may fill out forms incorrectly and fear to expose their ignorance by asking for help).
- Negotiation of the health care encounter (Patients may be unable to follow directions, understand signage, keep appointments, or locate clinics).
- Management of the medication regimen (Patients may have difficulty understanding and following instructions, organizing regimens, recognizing side effects/outcomes, and communicating about adjustments);
- Management of administrative aspect of health care (Patients may not be able to fill out insurance forms, make sure prescriptions are refilled on time, or apply for Medicaid);

- Health care workers' treatment of the patient (providers and staff may explain less to low literacy patients, use jargon, and express impatience with patient ignorance and inability to fill out forms).

#### 4. Conclusions—research and programmatic directions:

In sum, although the magnitude of illiteracy and its relationship with health is established, we know little about the mechanisms through which literacy impacts health. Likewise, we know that current written materials for patients are poorly matched to population skill levels, but know little about the effect of providing materials written at lower grade levels or providing alternative forms of patient education that minimize the need for literacy. We urgently need both basic and applied research on how literacy affects the various processes necessary for all aspects of prevention, screening and management in chronic disease such as arthritis.

At the highest level, illiteracy is a social problem best tackled by better literacy education for children and adults. In the meantime, certain steps may help those adults with arthritis who currently have difficulty with reading:

- Rewrite arthritis patient educational materials in Plain English (5<sup>th</sup> to 8<sup>th</sup> grade level), with attention to established principles of organization, type size, layout, and illustrations (30).
- Train providers in ways to recognize when patients have low levels of literacy and better ways to communicate with them.
- Develop and test alternative educational methods for patients and the general public that do not rely on the written word, but take into account ways in which poor readers (and non-readers) attend to, process, and act on orally and visually presented health information and behavioral modeling.
- Adapt currently successful educational programs, such as the Arthritis Foundation series, for low-literacy patients.
- Redesign medical forms, instructions, signage, and bureaucratic processes to take into account that a quarter to a half of users may lack the ability to follow directions accurately without help.
- Make educational messages and materials culturally relevant for subgroups at highest risk. Attention to cultural meaning and use of language and illustrations is especially important in groups with low literacy, because interpretation of illustrations and behavioral modeling may be particularly sensitive to cultural context among persons who cannot read accompanying text that could clarify the meaning of illustrations.

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## A Community Model for Spanish Language Arthritis Program Delivery and Evaluation

Lori Harrison Port, M.P.H.

### Purpose:

To deliver high quality, effective, Spanish-language arthritis self-help programs in the Arthritis Foundation, Southern California Chapter area.

### Background:

The Hispanic population comprises over 40% of the population of Los Angeles County, or over four million people. According to the United Way of Greater Los Angeles, more than half of the Hispanic residents in Los Angeles do not speak English, do not have health insurance and have not completed a high school education. The majority of these residents were born in Mexico. United Way data for Hispanics residing in Orange County is similar: 34% of the population is Hispanic and 556,000 reside in the program target areas, most of which are indigent.

A needs assessment conducted by the Olive View–UCLA Medical Center Foundation in the North San Fernando Valley area indicated that arthritis was seen as a priority issue among Hispanics residing in the surrounding communities. In Orange County, arthritis was the most common complaint of farm workers as reported in a 1988 report in *Occupational Health*. In 1997, the CDC reported that arthritis was the second most common self-reported chronic condition among Hispanics (*MMWR, 1997*).

Few resources have been available in Spanish through the Arthritis Foundation. Since the mission of the Arthritis Foundation is, in part, “to improve the quality of life for persons with arthritis,” the Arthritis Foundation, Southern California Chapter decided to address the large numbers of Hispanics with arthritis in its service area. This abstract addresses programs developed in the North San Fernando Valley (Los Angeles County), Orange County, and East Los Angeles.

### Objectives:

- Improve functional status and quality of life for people with arthritis including pain and depression ratings, use of self-management skills, and appropriate health care provider visits.
- Implement community-based and community-driven arthritis self-management programs for low income, Spanish-speaking people.
- Evaluate the effectiveness of all programming.
- Collect data regarding the knowledge, attitudes and behaviors of Hispanic people with arthritis and their primary care providers.

### Methods:

Arthritis Foundation volunteers at Olive View-UCLA Medical Center, Division of Rheumatology and Foundation (a private, not-for-profit arm of the Medical Center with a mission in patient education) embarked on delivery of a Spanish language program in the community using the *promotoras* system. This is a classic public health, grass roots method of health education delivery. Lay leaders (*promotoras*), Spanish-speaking and of Hispanic descent, were recruited from the community and a bilingual Spanish/English health education coordinator was hired. Most of the *promotoras* were already trained and working as prenatal educators in the community so they had experience in health education methodology. Working with the Stanford Arthritis Center, the health educator and *promotoras* were trained in the Spanish Arthritis Self-Help program, developed by Kate Lorig, DrPh and Virginia Gonzalez, MPH. The Arthritis Foundation, Southern California Chapter, participated by providing partial grant funding and staff and volunteer assistance in developing and promoting the program. The program was launched in 1997. There are currently 29 sites offering the program including churches, schools and other community sites. Instructors are paid a stipend through Kelly Services, which also affords them some benefits.

In 1998, the Arthritis Foundation, Southern California Chapter, Orange County Branch, launched a similar program in five cities in Orange County, using a similar model as in the North San Fernando Valley. In Orange County, the *promotoras* found were working in diabetes patient education in the community. *Promotoras* for our program were recruited and trained and are currently given stipends by the Arthritis Foundation. They offer programs through a network of schools, churches and other community sites. Programs are also offered in cooperation with the Orange County Department of Health (public health nurses) and local hospitals. Initial support came through a discretionary grant made by United Way of Orange County. Subsequent (and current) funding is provided through the California Department of Health Services through the CDC, National Arthritis Action Plan initiative.

Other features common to both programs include a community-based, rather than hospital-based approach, and lay leaders are recruited from the Hispanic community, rather than using health professionals from other communities. Both offer certificates of completion and a festive, healthy potluck meal upon completion of the program. This is attractive to the participants. Family members and friends are encouraged to participate. Attendance has grown each year in all programs due to word-of-mouth referrals.

In 2000, the CDC awarded USC a grant to deliver the Spanish Self-Help program to the East Los Angeles community and to evaluate the burden of arthritis in the community through the use of social market research. Primary care providers in the community will also be queried about their knowledge, attitudes and behaviors regarding self-help and rheumatology specialty referral. The grant was written in collaboration with the Arthritis Foundation, Southern California Chapter. The chapter will be responsible for the program delivery and evaluation components of the grant. In addition, exercise programs will be offered and evaluated. These programs will commence in the late fall of 2000 and run through 2001, and there is already have a growing wait list of residents eager to enroll in the programs.

### Results:

Over 800 people have taken the program in North San Fernando Valley and over 300 people have taken the program in Orange County.

Evaluation format includes pre/post and four-month follow-up questionnaires. Instruments used include: pain visual analog scale, arthritis knowledge scale, self efficacy scale, general health rating, mannequin tender and swollen joint counts, number of MD visits in last four months, and the health assessment questionnaire (HAQ).

Both programs have been evaluated with positive results in the areas of knowledge, general health, efficacy in dealing with pain and other symptoms, depression and coping with daily activities. Comments indicate high satisfaction with program and improved communication with others about arthritis. There was no change in tender/swollen joint counts as expected. There was a reduction in health care provider visits seen in both studies at the four-month follow-up.

### Conclusions:

Partnering with community agencies and organizations serving the low income, Hispanic community is a feasible method of delivering high quality, low cost programming to people with arthritis. Lay leaders representative of the Hispanic community can often be found through existing prenatal and diabetes education community services. Successful program implementation often depends on outside funding for recruitment, training, and retention of a coordinator, lay leaders and delivery of programs. Program success also depends upon the establishment of appropriate community networks, and positive word-of-mouth referrals. Four-month follow-up results indicate positive results in pain and depression management, knowledge and self-efficacy. Continuation of funding will be important for the maintenance of these programs and continued evaluation.

## **Outreach Models For Culturally Diverse Populations: Laying the Groundwork For Evaluating Programs to Correct Disparities**

Laura Robbins, D.S.W.

With the rapidly changing demographics of the U.S. population, there is an urgent call to action to develop effective models of change to reduce health disparities and develop model outreach programs.[1,2] While many factors such as socioeconomic status and level of education may influence health care, little is known about the role of culturally determined beliefs and subsequent health behaviors in reducing these disparities.[3] Qualitative methodology is evolving as a scientific tool for assessing cultural beliefs and behaviors in order to develop effective community-based programs aimed at reducing health disparities. We report here on an outreach model based on over 12 years of experience working in Latino and Asian communities. We will illustrate the model with two Department of Health Programs: (1) The Pediatric Outreach Musculoskeletal Program, and (2) New York State Osteoporosis Prevention thru Education Program (NYSOPEP).

Our cross cultural outreach model utilizes ethnographic research based on the “emic” and “etic” theoretical framework. The emphasis is on preserving and capturing health belief and behaviors that are indigenous to the specific cultural group.[4] It is based on the group’s report of beliefs, and observed and reported behaviors through the use of key informant interviews and focus groups. Data is analyzed and then applied through active rather than passive dissemination. Active dissemination has been proven successful through developing a collaborative environment within the community that provides incentives for change. Findings are also then used to develop musculoskeletal education programs. These programs build upon cultural universals and have demonstrated success in reducing health disparities.[5]

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## Outreach Models for African American Communities

Oretta Mae Todd, Ph.D., M.S.N., C.N.M.

**Arthritis Awareness: Urban Outreach (AA: UO)** is a model designed to increase access and to teach arthritis self-management to urban African Americans in the City of Detroit. Under the aegis of the Arthritis Foundation, the model reaches out to African Americans who are most at risk for arthritis and who tend to experience more physical limitation from the disease than other groups. Working with individuals from the faith-based community, the model applies the work of Lorig and Fries, using the Arthritis Self Help Course to cover essential health and self-management strategies that a person with arthritis or an arthritis care-giver needs in order to cope with activities of daily living.

With a grant of \$35,000 from the Michigan Department of Community Health, AA:UO was launched in 1995. The goals of the program are to:

1. provide, without cost, opportunities for participants with arthritis and/or their care-givers to gain knowledge about the disease, to learn self-management skills, and to change behaviors, thereby enabling persons with arthritis to improve their quality of life, lessen pain and reduce the number of physician visits for arthritis.
2. recognize the participants' initiative to attend classes and reward the personal motivation that is necessary to better manage health and change behaviors
3. collect data that quantify the Arthritis Self Help Course as a successful vehicle for positively effecting change in the psychosocial, behavioral and social impact of arthritis on urban Black Americans.

The University of Michigan Multipurpose Arthritis and Musculoskeletal Diseases Center (UM/MAMDC), is a partner in the project, evaluating the model in relation to:

- the impact of arthritis patient education on arthritis symptoms and pain level, functional status, self-care knowledge and behavior
- impact of focused reinforcement of the concepts in ASHC over a 12-month period
- examining the relevance of ASHC to an urban Black population

Analysis of outcomes gathered about the AA:UO participants show the following:

1. 67 classes with more than 1000 enrollees
2. 75% Women; 25% Men
3. 97% African Americans
4. Education – Average High School; 51% have one yr college, inc leaders
5. Income Average \$11,000 – \$29,000 ( 67% responding)

At request of participants, an Arthritis 101 class was developed to reconvene a pilot group to review concepts that need reinforcement and compare results with controls.

Focus groups were used to delineate strengths and weaknesses of the classes:

- Michigan is perceived as a leader in arthritis education
- Communication was enhanced, particularly with physician
- Key elements of class seen as components applicable in other chronic diseases
- Arthritis education helped to improve the quality of their lives.

## Session I

Graciela S. Alarcón, M.D., M.P.H.

1. Why do ethnicity and race need to be defined in clinical research?
2. Is ethnicity a proxy for race (and thus does it have specific biological implications)?
3. Is ethnicity a proxy for socioeconomic status, and if so, why don't we measure its components?

Raynard S. Kington, M.D., Ph.D.

1. Where are the places in the causal chain of events leading to racial and ethnic disparities in treatment and health outcomes that may be most susceptible to interventions?
2. How are possible changes in the health care system such as more restrictive managed care and prescription drug coverage likely to affect existing differentials in diagnosis and treatment?
3. What types of methodological and data needs must be addressed in order to extend our understanding of the causes of differentials and the development of interventions to address disparities?
4. What are the pathways by which cultural differences lead to differentials in health and healthcare? How will these cultural differences among groups as well as varying definitions of race and ethnicity affect our ability to address differential treatment and diagnosis?

## Session II

Patricia A. Fraser M.D., M.P.H., M.S.

1. What multidisciplinary research approaches might be used to facilitate the study of gene-environmental interactions and disparities in connective tissue and musculoskeletal diseases?
2. Are there biological markers or assays that should be incorporated into the study of gene-environmental interactions and disparities in connective tissue and musculoskeletal diseases?
3. What is known about the genetic determinants (e.g., leptin genes) for behavioral factors (smoking, dietary preferences, excess dietary intake) that influence disparities in connective tissue and musculoskeletal diseases?

### **Session III**

Kate Lorig R.N., Dr.P.H.

1. When do you think you can mix cultural/ethnic groups, and when must programs be provided separately?
2. How do we begin to develop programs that will reach more than a very small segment of our ethnically/culturally diverse populations?

## Session IV

Joanne M. Jordan, M.D., M.P.H.

1. Do we have sufficient information now to design interventions to eliminate disparities? If not, what data do we still lack? If so, how can we design interventions now?
2. Are there any "generic" principles that can be applied to the development of interventions across ethnic groups? If so, what are they? That is, can we apply what has been learned in one ethnic group to the design of interventions for another ethnic group? Or is each ethnic group sufficiently unique that we cannot apply, even partially, a "one size fits all" model?

## Session V

Matthew H. Liang, M.D., M.P.H.

1. Which research initiatives would have the widest impact across the range of diseases/conditions where there have been demonstrated disparities?
2. What are the major barriers to implementing programs to eliminate disparities?
3. What are the major research questions regarding studies in underrepresented minorities with health disparities?

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